

Margaret Flinter: Welcome to Conversations on Healthcare with Mark Masselli and Margaret Flinter. A show where we speak to the top thought leaders in health innovation, health policy, care delivery and the great minds who are shaping the healthcare of the future.

This week Mark and Margaret speak with Dr. Tom Delbanco of Harvard, Founder of OpenNotes, a movement he started to make clinicians notes available for patients to view in an Electronic Medical Record. He launched the effort a decade ago with much pushback from the medical establishment, but they have just passed the 40 million patient threshold. He talks about how it enhances patient engagement and improves patient satisfaction.

Lori Robertson also checks in, Managing Editor of FactCheck.org looks at misstatements spoken about health policy in the public domain, separating the fake from the facts. And we end with a bright idea, that's improving health and wellbeing in everyday lives.

If you have comments, please email us at www.chcradio@chc1.com or find us on Facebook or Twitter, iTunes or wherever you listen to podcast. You can also hear us by asking Alexa to play the program Conversations on Healthcare. Now stay tuned for our interview with Dr. Tom Delbanco of OpenNote here on on Conversations on Healthcare.

Mark Masselli: We are speaking today with Dr. Tom Delbanco Professor of Medicine at Harvard Medical School and Co-Founder of OpenNotes, an international movement to give patients access to clinical notes in their electronic health record. Dr. Delbanco was Chief of the Division of General Medicine and Primary Care at Beth Israel Deaconess Medical Center in Boston and also created the Harvard Medical School Faculty Development and Fellowship Program. Dr. Delbanco earned his Medical Degree from Columbia University and we welcome you to Conversations on Healthcare.

Tom Delbanco: Terrific to be talking with you.

Mark Maselli: Your main mission in life has been to draw closer to those that we serve and it's no surprise that you launched OpenNotes a decade ago in an effort to empower patients and to give them access to their provider's clinical notes and their electronic health record and we celebrate with you, it sounds like you got a milestone recently over 40 million patients have now engaged in OpenNotes through their electronic health record and I am wondering if you could share with our listeners, the origins of OpenNotes movement with us and how this once radical idea has now taken root as part of the mainstream.

Tom Delbanco: In 1973 I woke up one morning to read an article in the New England Journal of Medicine, saying we could really share our records, our notes and everything we do with our patients. A light bulb went up for me and that light bulb was actually supported further by an experience I had with a new patient a few years later. I met primary care doctors and I got a new patient one day who was sent to me actually by his family because his blood pressure

was hard to control. When I took a history from him as you do and I learned from him that he was having a little trouble at work, he was having trouble with his blood pressure, he was having trouble with his spouse; wasn't enjoying life very much, smoked, had a couple of beers a day. Then I also realized he was also a printer by profession. And printers in those days could read everything upside down as a result of that. So I said to him, "Mr. A I assume you can read everything that I am writing." And he said, "Yeah that's true doctor." And I said, "I am in a bit of a quandary I think listening to your history, that you drink more than 2 beers a day, and that you are probably in the early stages of alcohol abuse. But I don't know whether I should write that down or not, because there is no point in my writing it down, if you don't agree with me." And he said, "Doc you better write it down." That proved actually to be a turning point in his history and he was able to stop drinking too much and life got a lot better for him. And that was another light bulb for me.

Then what happened of course is we got computerized medical records, we got them very early at our hospital in Boston. And that was the end of the world for the doctors, but then they got used to it. Then in the late 90s we did one of the earliest patient portals in which we offered patient access through secure internet processes to reading about their last test, looking at their problem list, looking at their medication list and that was the end of the world for the doctors, but then it proved not to be the end of the world.

Then Jan Walker and I, Jan and I have worked together for 30 years. Jan is a nurse by training, but a health services researcher. We kind of said the next step is why don't we invite patients to read everything we do including what we write about them. We went to the Robert Wood Johnson Foundation. They were kind enough to give us a planning grant and then more grants and we had an extraordinarily exciting adventure in the past 10 years as a result of that.

And kind of strange but traditional course of innovation in healthcare, it usually comes from one patient, usually comes from one insight or one thought by one person and then it blossoms into something that hopefully can be exciting, usually it isn't, but this has been one of the lucky breaks for me and a very exciting adventure.

Margaret Flinter: Well from what I understand the patient's response to, your printer patient who was able to read his notes upside down and really responded with openness and truthfulness in a way that could allow you to help them was maybe a little bit of a different reaction than what I have understood you had when you floated the idea of OpenNotes to the provider community. And there was a real concern that it might add unwanted burden to the workflow of the providers and patients maybe kind of be trusted with all that information, but you have done the research to show that patients have responded favorably, it has benefited them but the clinicians also report that there is benefits. Maybe share with our listeners a little more about what you

have learned from the research that you have done.

Tom Delbanco: Well we wrote a paper in the Annals of Internal Medicine I think in 2010 in which we just suggested the idea once again that with the use of electronic records now patients should be invited to read notes. The editor of the Annals got a normal scatological letter from one of the regions of the American College of Physicians which published his Annals saying this is the craziest idea I have ever heard of. Doesn't Dr. Delbanco and his colleagues understand that records belong to doctors, they are the domain of the doctors. Doctors use them to remind themselves of patients to communicate with other colleagues, they are already too many people looking at records such as insurance people and quality people and where does he get off saying that now patients and their family should also be part of that.

So there was real resistance, and one of the big institution that is yet to adopt OpenNotes, one of the trustees who is a physician is said to have gotten up and said you are going to do this over my dead body.

Margaret Flinter: The proverbial dead body sir.

Tom Delbanco: So we went ahead and did this pilot study with 20000 patients and a 100 primary care doctors who volunteered in Boston at our hospital at the Geisinger Health System in Pennsylvania which is slightly rural, less educated people, quarter of them had not gotten out of high school. And then we did it with a safety net hospital in Washington State at the University of Washington. We just like did it for a year and we asked doctors and patients at the end of that year what was it like? The patient absolutely loved it. I mean I have never seen a study in my life when 99% of anyone says anything about something, but 99% of the patients thought it was the right thing to do and liked it, they felt more in control of their healthcare, they remembered what happened in visits better. Remember that when you go to see the doctor, you remember about 50% of what he or she said and of that you remember about half thereon. That's been shown in many studies and it's the worst time in the world, to educate anyone about anything. They were able to go home and cogitate, think about what was going on and digest it, look things up and they felt terrific about it. They also wanted to share it with other people in their home and 80% in our very first study said, this is something that I really wanted to have, that it would determine my choice of the next health professional I go to.

Now the doctors on the other hand were worried about two things primarily, one was that it would interfere with workflow. Doctors, 9 years ago were stressed, doctors today are even more stressed. Doctors are disparated bunch much too often, certainly primary care doctors and even though these doctors only were volunteering and knew they could stop after a year, they were very worried that they would interfere with the way things went. They were also very worried that they would scare their patients. Well it turned out that their workflow was not perturbed, the email traffic did not change, we counted that. The biggest, most common question I was actually asked by

the doctors in that trial was, “Are you sure the computer is working?” They virtually noticed nothing while the patients were having a wonderful time with this. The patients were also reporting that very few of them were worried or confused or agitated by the notes.

So that was a very good sign and that really we published that now in 2012 7 years ago and now we are as you mentioned at a point where 40 million Americans have electronic access to notes through patient portals in which they registered.

Mark Masselli: I want to pick up on that theme, you also have some really significant health systems that are using these, you mentioned Geisinger, Mayo Clinic, Kaisers involve the VA as well. I am wondering as you sort of look at what is sort of straightforward and simple, how has it impacted the clinical practice and outcomes as well?

Tom Delbanco: So we have very few studies yet that show differences in clinical outcomes. What we do have is much, much more data replicated from many centers now, we have 200 centers involved with OpenNotes. Extraordinarily similar reports from patients and doctors about their experiences with OpenNotes, we did do one study in which we were able to compare patients with OpenNotes, patients without OpenNotes and the way they refill their medicines if they had high blood pressure. We were gratified to see that in those who read their notes or those who actually had access to their notes, had higher refill rates of their medicines than those who did not have access.

That’s the only really formal outcome study that we have so far. On the other hand we have institutions trying a little [inaudible] [00:10:52] and saying we are going to do this and it’s useful for our patients and it’s useful for us. We have many, many anecdotes about patient safety, two eyes on chart are better than two eyes on a thousand charts. When you have got a patient reviewing his/her records and saying there is a mistake here, it’s the left knee not the right knee, I missed that lump or the doctor missed that lump, I was supposed to follow through on it. We have many rather exciting and sobering anecdotes now in the patient safety arena which says this really increases safety, but I think it’s a very important part of it.

We also --; adherence to medications, we just published a paper in the last few weeks in the Annals of Internal Medicine showing that patients say very firmly that they are understanding their medicines better and that is 15% to maybe 40% of patients say they are taking their medicines more effectively. It costs our nation \$300 billion a year to have poor adherence to medications. If you do a little bit of math and you extrapolate to more patients reading their notes, that to me as a doctor is maybe the most exciting finding we have so far.

Margaret Flinter: Well much of your work is, I have read about it, it has really been about creating a healthcare system that is really designed through the patient size. And I have picked up on a comment that you made in one of our

articles. You said that most clinicians believe that they are the ones who are saving patients but you believe it's actually the patients who can save the clinicians maybe expand on that a little bit.

Tom Delbanco: Doctors and nurses but doctors in particular are having a very hard time right now. And they have lost a lot of their persuasive authority, they feel like of disempowered, they feel that they are run by corporations now, controlled by corporations. As you probably know there is a very high burnout rate among doctors and they are a disparated lot. The people they feel closest to are their patients and the mechanisms that I believed in I think will bring them closer still to their patients. Patients are our citizenry --, they are the consumers of the world, there are 340 million American patients that are not nearly as many doctors. I think it's when the citizen really wakes up and stands up and says you have to change the circumstances for us as patients and for those who are caring for us as doctors, a meaningful, positive change will occur.

So that's the sense I have said that patients will rescue us. If they care about us, if we care about them, I think they will be our salvation rather than we being their salvation. Basically we are talking about a partnership right and that's everything that I have been working on. I am a little bit of an optimist, I am a little bit of an idealist, but that's where that came from that kind of comment.

Mark Masselli: Well that's great. We are speaking today with Dr. Tom Delbanco, Professor of Medicine at Harvard Medical School and Co-Founder of OpenNotes. Tom I want to sort of hold a thread on someone who is seasoned I would say in the health system about how you are reimagining the future of the health system. We had the opportunity of having one of your colleagues on Dr. [inaudible] [00:14:01] demonstrating his work in sort of voice activated interfaces with Alexa. I am wondering if you could talk a little bit about your vision or the next phase around empowerment and the role technology will play as we look out in horizon.

Tom Delbanco: Well if your patients don't get more engaged in their own healthcare actively, we are going to be in an even more soup than we are in now. The engaged patient there is lots of data now, the engaged patient has better outcomes, does better, costs the system less money and improves the quality. Any strategy that is directed toward engaging patients actively in his/her care is very important to do.

While my friends at the American College of Physician said that doctors own records I think that is changing and that I would say that right now, patients and doctors probably jointly own records and my vision for the future is that patients will own the record. That's true interestingly in many countries that we call developing countries, because of apps, because of electronics, because of the need for interoperability, the need for one institution to be able to talk to patients and another one and to have patients have it all together, that's inextricably what's going to happen. You are going to soon

have on your cellphone or on your watch or on your whatever you are going to have all your records together. In fact you are going to have to manipulate them, control them, integrate them that's certainly the vision that I have and also my close friends. And that involves engagement and control. I learned early on it's totally impossible to predict what the model is between the patient and the doctor, unless you ask them. I would ask my patients, you want me to be stern and distant, you want me to be warm and cuddly, are you a first name person, that I would write it down and then I would try and assume that role with what patients are comfortable.

Some patients are going to want to master all their record, but we have to begin, I think in pre-kindergarten. I asked my six year old grandson two years ago, "You want to read your notes?" His response is perfect, he says, "If mom says it's okay I would like to read." Young people are much more used to transparency. We are talking about really open communication. We have to develop a healthcare system that can do that. It will save us money, I think it will improve longevity which is a problem, because as people live longer, they cost more money someone once taught me that if everyone stopped smoking right away that would bankrupt our healthcare system --.

Margaret Flinter: When you look back on your wonderful long history in healthcare and in education and in medical education, give a sense of what you see as the big transformation, the way we educate and train that next generation or visions that the healthcare providers that engages the patients, shares with the patient, has healthcare education really changed to embrace this model.

Tom Delbanco: I think if we become instantly better over the years at teaching young health professionals what it is to be with a person. How it is to listen? How it is to develop more empathy? How it is to think about the whole person? I think we become instantly better at that than my teachers help me be when I was a young doctor. The paradox is I think that this people know much less medicine than I did. There is only certain amount of time in a day and I was basically learning different heart murmurs and different heart sounds and what it was to examine the abdomen and I think, I am much better at that than the young doctors of today.

There is no question that young people today, of course are much more technologically savvy. There is no question that I think they are more used to transparency. I think we need to mobilize patients as teachers. They can be our best teachers. I had many patients who I would put in rooms with my medical students and I wanted to give them Harvard appointment, because they were far better teachers to my students than I was, I thought many years back. I am very bullish about young people, they will be much better at things in the end than I am. It will be an exciting evolution to watch, I hope I am around to watch some of it. It will involve technology for sure, but for every time we go up, we take a few steps backwards and how we will come out is not so easy to say.

Mark Masselli: We have been speaking today with Dr. Tom Delbanco, Professor of Medicine

at Harvard Medical School and cofounder of OpenNotes, an international movement to give patients access to clinical notes in their Electronic Health Record. You can learn more about his important work by going to www.opennotes.org or you can follow them on Twitter @myopennotes. Dr. Delbanco, thank you so much for your decades of dedication and for joining us on Conversations on Healthcare Today.

Tom Delbanco: My pleasure. Thank you very much for inviting me.

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Mark Masselli: At Conversations on Healthcare, we want our audience to be truly in the know when it comes to the facts about healthcare reform and policy, Lori Robertson is an award-winning journalist and Managing Editor of FactCheck.org, a non-partisan, nonprofit consumer advocate for voters that aim to reduce the level of deception in U.S. politics. Lori, what have you got for us this week?

Lori Robertson: On the campaign trail, former Vice President Joe Biden and President Donald Trump have both claimed that a cure to cancer would soon become a reality, if they were elected in 2020. Experts however, don't share that degree of optimism. Despite considerable progress, especially in recent years, cancer isn't one disease to cure and advances in all the many types of cancer are likely to take multiple decades. In a speech in Iowa, on June 11th, Biden said, "I promise you, if I am elected President, you are going to see the single most important thing that changes America. We are going to cure cancer." A week later on June 18th Trump made a similar statement during his 2020 kickoff rally as he listed several agenda items for a second term. He said, "We will come up with the cures to many, many problems to many, many diseases including cancer and others."

While both politician suggested these cures would come while they were still in office, neither explicitly said, when exactly this would happen. But oncologist say, curing cancer is unlikely to happen within the next decade. The first problem with both politician statements, several experts told us, is that cancer isn't a single disease. Timothy Chan, a physician-scientist at Memorial Sloan-Kettering Cancer Center told us the name cancer applies to hundreds or thousands of types of diseases. Given that curing cancer would mean finding many cures, Chan said, "Doing so would be "impossible" in the next 10 years." "Maybe the next 50 years to cover everything" he said.

Even if all cancers can't be cured soon, multiple experts were quick to point out that some cancers can already be cured, no advances needed. Researchers are encourage about many newly developed treatment such as immunotherapies that take advantage of the body's immune system to attack cancer. Regardless of who wins the White House in 2020, experts told us the way to speed up progress on cancer is to pay for more research, without funding breakthroughs can't happen. For more on this topic, see our website at FactCheck.org. I am Lori Robertson, FactCheck's Managing Editor.

Margaret Flinter: FactCheck.org is committed to factual accuracy from the country's major political players and is a project of the Annenberg Public Policy Center at the University of Pennsylvania. If you have a fact that you would like checked, email us at www.chcradio.com, we will have FactCheck.org's, Lori Robertson, check it out for you, here on Conversations on Healthcare.

[Music]

Mark Masselli: Each week Conversations highlights a bright idea about how to make wellness a part of our communities and everyday lives. For all the people in the world without limbs acquiring prosthetics can be costly and out of reach. It's especially challenging to make prosthetics for children, since they are in constant state of growth. Rochester Institute of Technology, scientist Dr. Jon Schull stumbled upon a clever and affordable solution, provided online, Open Source templates to anyone, anywhere in the world who has access to a 3D printer and provided prosthetic hands for next to nothing.

Jon Schull: I had made this Google maps mash up. If you have a 3D printer and you would like to help, put yourself on this map and if you know someone who needs a hands, put yourself on this map and by going something like this get going.

Mark Masselli: He found as he e-Nable network which has massed thousands of volunteer makers in upwards of 40 countries around the world providing cheap, but functional prosthetics for children in need.

Jon Schull: I think we are currently pushing 5, 800 identified members in our Google Plus community. We have followings in the thousands more. We know that we have delivered about 800 hands devices and we suspect for this comparable number have been downloaded by people we can track, because we put all of our designs on the internet.

Mark Masselli: The movement has grown so rapidly that simple limb designs have become more sophisticated as recipients of the prosthetic devices provide feedback for designers to make more efficient devices.

Jon Schull: We are still working on the appeasable firms. We are still working on the individual finger movements, these things grip or ungrasp that's all they do, so they are much less functional than our biological hand and they are also less functional than a fancy myoelectric hand. But for kids it's huge because those expensive devices that are typically out of reach for children who would outgrow them so it doesn't make sense for them to get a \$5000 or \$10000 hand. Our hands don't even pretend to look like regular hands, they look like superhero, Iron Man hands and for that very reason, they are very popular with kids.

Mark Masselli: e-Nable a global collaborative network of Open Source designs linking to makers with 3D printers to provide low cost prosthetic limbs to children and adults around the world who might otherwise not be able to afford them, now that's a bright idea.

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[Music]

Mark Masselli: You have been listening to Conversations on Healthcare. I am Mark Masselli.

Margaret Flinter: And I am Margaret Flinter.

Mark Masselli: Peace and health.

Moderator: Conversations on Healthcare is recorded at WESU at Wesleyan University, streaming live at www.chcradio.com, iTunes or whatever you listen to podcast. If you have comments please email us at www.chcradio@chc1.com or find us on Facebook or Twitter. We love hearing from you. The show is brought to you by the Community Health Center.